

Data Sharing and Dissemination Strategies for Fostering Competition in Health Care

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Objectives. To introduce the concept of common models for data sharing and dissemination, highlight the current operational, technical, and political issues surrounding existing data sharing and dissemination initiatives in a health care market, and suggest an ideal model for future data initiatives.

Data Sources/Study Setting. A literature review and case studies of existing data sharing and dissemination initiatives that promote the collection and use of comparative information on provider cost and quality.

Principal Findings. Three broad types of common models for data sharing and dissemination have evolved over the past decade or so: (1) provider-initiated initiatives developed through collaboration among providers of health care; (2) purchaser-initiated activities driven by a coalition of purchasers; and (3) indirect collaboration—data-sharing initiatives between providers and purchasers with a significant facilitating or regulating role by a third group of stakeholders. The success of a data-sharing and dissemination strategy is determined by how the complex operational, technical, and political issues are addressed. General principles by which a health data initiative might abide include the following: standardized databases as the physical foundation, indicators that reflect the changing market; linkages between and across data sets for comprehensive and complete data; economic value; policy relevance; use of evolving technologies to collect, integrate, and disseminate data; and stakeholder support.

Conclusions. Regulatory solutions alone will not overcome the complex political and technical challenges to data sharing and dissemination. The “ideal” model or process nurturing a market for health care information will incorporate compromise and negotiation to address the issues of data ownership and proprietary concerns, therefore securing the necessary political and financial support of the private sector.

Key Words. Health care market, health information, data sharing, data dissemination, health care purchasers, health care providers

Perhaps the cornerstone of a competitive market is a level of information that allows purchasers to compare the price and quality of services across providers. This link between information and competition in health care has dramatically grown in importance as indicated by the proliferation of data sharing and dissemination initiatives in the health care market. It is important for policymakers, purchasers, and suppliers to understand the complex operational, technical, and political issues surrounding common models of data sharing and dissemination. The first part of this article describes these models and evaluates their relative strengths and weaknesses in fostering competition in the health care marketplace. The second part describes the essential elements of what the authors envision as an ideal data-sharing and dissemination model that builds on and incorporates the strengths of the models reviewed.

COMMON MODELS OF DATA SHARING AND DISSEMINATION

The major stakeholders involved in health care market competition are the providers of the goods and services (physicians, hospitals, health insurers), the purchasers (employers, individual consumers, public health), and a third party that facilitates or sets the rules for the exchange and use of information. Motivations and incentives surrounding the use of shared information vary according to the stakeholders involved.

Purchasers, according to conventional economic assumption, will use information to make health care decisions. Underlying this is the premise that consumers will choose from the array of available options with knowledge of the relevant information and with the wisdom to optimize their outcomes. This assumption is the bedrock of the movement toward consumer-oriented, market-based health care reform (Eisenberg 1998). However, the complexity of medical decision making, the amount of information necessary to make

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choices, and the pooling of risk through insurance means that, unlike most markets, individuals may not necessarily be the primary decision makers in the health care services markets (CAMC 1997).

On the provider side, the economic perspective is equally weak as a basis for fostering competition. Whereas in other market settings we expect financial gain to be the primary driving force in the production and exchange of commodities, we expect a “patient first” ethic in health care. Health care providers are expected to be motivated primarily by patient need rather than economic self-interest (CAMC 1997). Thus, although providers’ uses of shared information usually involve examination of market shares, utilization projections, and cost benefit analyses, they also address strategies for achieving efficiencies, higher quality of care, better outcomes, and greater patient satisfaction.

Third parties rely on shared information to monitor the care received by constituents and for purposes of promoting accountability. A third party may be a government agency mandated to generate and disseminate information to consumers to guide their purchasing decisions and improve their access to preventive care. It may be an accreditation agency collecting information on provider performance as part of accreditation requirements and for benchmarking purposes. Or it may be a not-for-profit organization whose mission is to monitor the industry’s performance in improving access to quality and cost-efficient health care.

Given that stakeholders have different motivations for using health care information, it would be useful to look at data-sharing and dissemination initiatives in broad categories defined according to major participants. We suggest that major initiatives that have emerged within the past decade or so generally fall under one of three models. The first model refers to data-sharing and dissemination initiatives that develop through collaboration among providers of health care. The second model refers to initiatives formed by a coalition of purchasers. The third refers to those data-sharing initiatives between providers and purchasers, with a significant facilitating or regulating role by a third group of stakeholders.

This article introduces the concept of the common models for data sharing and dissemination but does not tackle the issues of why one model is selected over another in a given market or the relative successes of one model over another. The authors believe that the selection of a model may be a function of the orientation and background of the leaders or major players in a given market and the history of data dissemination activities in that market.

How a model is selected and how effective that model is in changing provider and consumer behavior are important questions that warrant further study.

Model 1: Provider-Initiated Data Sharing

Data-sharing arrangements among members of state hospital associations and interstate consortia of hospitals are examples of direct collaboration in a provider model. Providers voluntarily joining together to collect and share data for market share studies and quality improvement initiatives characterize this model. Operationally, participating competitors and peers collectively determine the rules, fund activities through membership dues or contributions, and share decision-making powers and responsibilities.

A provider-controlled model typically restricts data-sharing and dissemination initiatives to its member providers, not allowing direct consumer or public access to the information. In general, one major weakness of data sharing among providers is the proprietary nature of data that are utilized. The political nature of provider-driven initiatives is that they are generally voluntary, and the products are targeted to meet provider needs. Health services researchers working within provider systems often hold or create information that is proprietary in nature because their research questions focus on key issues in a highly competitive industry: health care costs, quality, access, and patient satisfaction. Even when those researchers publish results in the public domain, their findings may be used for proprietary purposes. For example, cost-effective smoking cessation programs, methods to measure functional status, sophisticated breast cancer screening programs, guidelines for the use of lipid-lowering drugs, immunization tracking systems, or risk-adjustment methods developed and described in the public domain may become a core business product or strategy for virtually any health care organization. In more and more instances the host health care organizations that employ researchers share the same competitive marketplace. This may complicate the ability to cooperate through common protocols or shared data. Analysis of important outcomes such as costs may require scrutiny of proprietary information, which companies do not want their competitors to see (Durham 1998).

Typically, therefore, in a provider-initiated data-sharing and dissemination model, release is limited to the coalition's members, although a growing number of hospital coalitions are expanding into community assessment. The level of public release in this model may be a function of the relative competition in a given market, where providers in larger markets may release information to the public, but under a purely voluntary and discretionary basis.

Despite the restricted access to the information, a purely within-provider sharing model, without dissemination to consumers, can foster competition indirectly. First, providers who are most effective in using results of data-sharing initiatives would be most successful in improving health care outcomes and thus in enhancing patient satisfaction and standing in the provider community. Frech (1996) noted that competition through reputation could lead to reasonably efficient markets; effective competition may develop even if only some consumers are well informed. Second, providers who are most effective in using shared data in increasing efficiency of health care delivery would be most successful in improving profitability and ability to pass savings on to consumers, employers, or health plans.

Model 2: Purchaser-Initiated Data Sharing

Many large companies and major coalitions of employers have been working to develop information systems for health care as a way to increase efficiency and improve health outcomes. With the support of organizations such as the National Committee for Quality Assurance (NCQA) and the Foundation for Accountability (FACCT), purchasing coalitions have introduced incentives to encourage health care payers and providers to improve their performance.

Private coalitions, such as the Pacific Business Group on Health (PBGH), and public sector coalitions, such as the California Public Employees Retirement System (CalPERS) and the State of Missouri's Consolidated Plan, have compelled health plan and provider reporting to leverage value-based purchasing and stimulate consumer choice. These coalitions, and others like them across the country, can leverage local market changes by linking performance with purchasing decisions (Miller 1996).

Performance indicators have become a tool in purchasing negotiations with health plans, and coalitions have effectively used competitive pressure to compel "voluntary" reporting by payers and providers in a market. Purchasers that have successfully induced reporting are now moving to action based on this reporting by rewarding high-quality care through financial incentives. For example, General Motors' (GM's) health plan ties salaried workers' premium contributions to the amalgamated cost and quality scores. In 1996 PBGH negotiated performance guarantees with 13 California health maintenance organizations (HMOs) on behalf of the 17 large employers in its Negotiating Alliance; nearly \$2 million, or 23 percent of the premium at risk, was refunded to PBGH by the HMOs for missed targets.

As demonstrated by the success of business coalitions that are leveraging improved performance, data-sharing models driven by purchasers may not

be perceived by providers as a level playing field. Moreover, sensitivity to data supplier burden may not be an overriding concern, and the methodologies and results may or may not be fully shared with data suppliers. Proprietary and public interests may be secondary to the goal of value purchasing by the coalition.

Model 3: Indirect Collaboration Through a Third Party

A third model of data sharing and dissemination has evolved to meet market information needs. Instead of providers or purchasers setting the terms with the primary purpose of meeting their respective market needs, a third party intervenes for purposes of accountability and consumer information. In general, we can call this the "report card" model, the most controversial of models, which has contributed to "lifting the veil of secrecy" surrounding the business of health care delivery (Millenson 1997). What began in the early 1980s as an activist approach to medical cost containment is now considered a mainstay of a functioning health care market, providing information for a broad audience [See, e.g., the various report card activities documented in Faulkner and Gray's compilation (Faulkner and Gray 1997, 1998, 1999)]. The collection and public dissemination of health care performance measures is designed to create competition based on quality of care. While provider accountability is a central element of this concept, public release of comparative performance information serves several functions, including accountability in health care delivery, consumer decision making, and purchasing decisions based on objective and credible information. Participation in a performance measurement and reporting effort may be compelled through regulatory means (mandates) or through competitive pressure (e.g., accreditation).

Regulatory models of data sharing and dissemination are best exemplified by state-managed health data systems. At least 37 states have legislation mandating providers, payers, or both to report health data for public consumption, with the intent to reduce health care cost and improve health care quality and access (NAHDO 1998). Some states use the information for regulatory purposes (certificate of need, rate setting) and others to foster market behaviors and accountability. As states become major purchasers of health care, the state is in a position to use comparative provider information in the same manner as the private purchasing community. One of the pioneers of state reporting is the Pennsylvania Health Care Cost Containment Council (PHC4). In 1986, the Pennsylvania General Assembly passed Act 89, creating PHC4 in an effort to understand the reasons for cost increases and bring them under control. Act 89 required more than three years of effort and was driven

primarily by a coalition of business and organized labor leaders working together to make market-oriented health reforms.

PHC4 operates under the principle that “health care information is the key to managing change” (PHC4 1999, pp. 3–5) and provides consistent, accurate, and credible information about the cost and quality of health care services in Pennsylvania. PHC4 has been a leader in the public release of physician and hospital-specific quality data with its *Guide to Coronary Artery Bypass Graft Surgery* (CABG) (PHC4 1998), which includes 1994–1995 risk-adjusted bypass patient mortality rates for Pennsylvania cardiac surgeons, hospitals, and 34 health plans operating in Pennsylvania. The *Guide* also lists the average amount the hospitals charged for the procedure, risk-adjusted length-of-stay figures for hospitals and health plans, and information related to the volume of procedures performed by hospitals and surgeons. Like its counterparts in other state data organizations, PHC4 draws technical assistance from community advisory groups, including experts in the field, to assure methodologies are scientifically sound.

PHC4 reports that 77 percent of the hospitals state that results of their performance data for CABG encouraged changes in administrative procedures designed to monitor the performance of cardiac surgeons and support staff (PHC4 1999). On the other hand, consumer interest lags. When asked, consumers found value in the CABG reports, but many were unaware of the reports or stated not having enough time to act prior to undergoing cardiac surgery. As consumers become more familiar with quality-related data, and as sources such as the Internet provide rapid and thorough access to health care data, we can expect consumer demand for the information to increase.

Provider resistance to public reporting of performance data by a government agency is generally great, especially in the initial stages. In this often tense environment, states must establish a high degree of credibility in conducting a fair and open process and producing results. This accountability in public reporting includes demonstrating sensitivity to proprietary interests in the local market, acknowledging limitations in the data, and involving data suppliers and other stakeholders.

Health report cards are not just occurring in the public sector. The increased availability of state provider data has contributed to the proliferation of proprietary performance reporting initiatives. One example of a proprietary data effort is Health Care Investment Analysts (HCIA). HCIA-Mercer ranks the top 100 hospitals in the United States according to several factors, including risk-adjusted mortality, complications, length of stay, expense per adjusted discharge, profitability, and productivity (Millenson 1997).

Another mechanism for sharing and disseminating market data is evolving rapidly, led by industry. These initiatives have taken on a regulatory flavor, but participation is voluntary. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) has created a national hospital database derived from its clinical indicators, and NCQA has done the same for managed care organizations through its Health Plan Employer Data and Information Set (HEDIS). For a common set of indicators, all participating institutions provide information on their experience to these monitoring organizations. These data are used for accreditation decisions as well as for external comparisons of organization performance (JCAHO 2000; NCQA 1997).

This model is characterized by a complex interplay of stakeholders with sometimes competing agendas, which involve balancing the opposing tensions of public good versus proprietary interests and accuracy and integrity in data with timeliness and cost-effectiveness. Moving forward despite the limitations in the data is a high-wire act because political support can be fragile.

ESSENTIAL ELEMENTS OF A DATA-SHARING AND DISSEMINATION MODEL

It follows from the preceding discussion that, regardless of the model and the major stakeholders, the success of a data-sharing and dissemination strategy is determined by how the operational, technical, and political issues associated with data dissemination are addressed. Operational aspects are factors associated with the establishment of a model and the "institutionalization" of health information collection and use. Issues related to governance and decision making, staffing, and funding fall under this category and also include stakeholder representation.

The technical aspects of successful data initiatives are associated with how the data are collected, managed, and used. Technical credibility relates to the quality of the data, integrity and openness in methodology (no "black box" when a provider's reputation is at stake), and a robust research agenda using evolving technologies and analytic tools (taking advantage of the dynamic nature of the Internet and evolving adjustment methods).

Politically, whether a model is regulatory or proprietary, the "ideal" is one in which the decision process weighs the inevitable compromises and

trade-offs related to comparative health information reporting. Central to success in a data initiative is building trust between all concerned in the process, including willingness to compromise. Other success factors include equity in access to information and results, consideration of proprietary and public interest, and objectivity and independence when releasing comparative reports. Patient privacy must be integrated into the process, as it is a complex issue that can undermine or derail the process if it is not properly addressed.

While no single approach will meet the cumulative and competing needs of all players in the health care industry and no ideal situation exists, we can derive from our review of existing models some general principles by which a health data initiative might abide to achieve its objectives.

Standardized Databases as the Physical Foundation

Databases form the building blocks or core of any data-sharing and dissemination strategy. Many of the databases used in data-sharing and dissemination efforts nationwide are administrative data sets generated as a by-product of the claims payment process. These include the Uniform Billing 92 (discharge data), the Health Care Financing Administration (HCFA) 1500 (professional/physician claims), and Medicare financial and utilization data, sometimes augmented by clinical information abstracted from the patient's medical record. Because the definitions and specifications of data elements as collected by states are based on national standards, they are familiar to providers, purchasers, and data users. Claims and discharge data are widely used due to the relative ease of collection and comparability across sites. These data lend themselves to linkage and are useful in evaluating patterns of care and documenting variations in practices as well as outcomes (Aday et al. 1998). Health care utilization databases are increasingly being developed, initially in the hospital inpatient setting but in the recent years expanding to noninpatient data sets.

Indicators That Reflect the Changing Market

The impact of managed care continues to shape the health care market. Models for the next generation of comparative reports on quality and health status measurement are needed to reflect these changes and monitor their effect on the health care system. Current report models are based on the market needs of the 1990s. For instance, using discharge data to evaluate market share of provider systems using diagnosis-related groups (DRGs) has been a common practice, but as care shifts to outpatient settings, new measures of market share are lacking, as are comprehensive outpatient data. How

tertiary, secondary, and primary care are defined is changing. The health care community must advocate for research and development to refine existing indicators and develop new ones that reflect current and future market conditions and practice patterns that emerge in the 2000s. Major efforts to construct and improve model indicators are currently underway through federal-state-industry partnerships. These include the Healthcare Cost and Utilization Project's (HCUP's) Quality Indicators (AHRQ 2000) and the Emergency Department Indicators System funded by the National Center for Health Statistics of the Centers for Disease Control (NAHDO 2000). Both efforts are working to enhance the utility of administrative data through acceptable and comparable measures of health care cost, use, and quality. Eventually, indicators derived from linked morbidity and vital records data will provide more robust sources of data in which child health, injury, maternal care, women's health, and racial/ethnic health indicators can be derived.

Linkages Between and Across Data Sets for Comprehensive and Complete Data

No single data source will likely ever provide a complete snapshot of health and health systems performance. Linkages are occurring today and will continue in the future, provided the data privacy and confidentiality issues are properly addressed. New models and partnerships, eventually guided by national privacy policies, will challenge today's concepts of data ownership and data sharing when linking across sites of care and data sources. Models for linking similar data sets across states include HCUP, which has developed a set of standardized indicators and data management procedures for integrating morbidity data across states. This administrative linkage of statewide inpatient data systems needs to expand to include additional states and to promote new models of linkage and data sharing using evolving technologies.

Economic Value

The data collection model of the 2000s will need to provide economic value to purchasers and providers by providing information that strengthens their decision making in a timely manner in formats that are relevant to their users. While improving health care quality and access must be among the primary objectives of data-sharing and dissemination efforts, the likelihood of sustained success is enhanced through effective use of financial incentives for participation. Spurred by consumer and policymaker demands for information, providers will continue to use information to identify best practices,

reduce medical errors and the costs associated with them, and enhance efficiencies in providing quality care. Purchasers will continue to use information to shape health benefit plans, differentiate providers, and delineate quality-cost trade-off.

Policy Relevance

In spite of the obvious need for information to inform health care policy and aid the function of the health care market, policymakers often face difficulty in assessing the value of information. Data and information initiatives must overcome the political barriers to collecting and disseminating information and find effective ways to translate relevant information to policy makers. Including policymakers in the national measures development initiatives and experimenting with information dissemination tools and formats relevant to this important constituency is essential to promoting the value and utility of information.

Currently emerging as a potential forum for development of indicators in collaboration with existing data-sharing and dissemination partnerships is the National Quality Forum (NQF). The NQF is a not-for-profit membership organization established in response to a national call for action to address the complex political and technical issues associated with patient safety. The NQF will work with its diverse members to achieve national consensus on standard measures for measuring quality and, presumably, establish a national framework and guidelines for disclosing this information to diverse audiences (NQF 2000).

Embrace Evolving Technologies to Collect, Integrate, and Disseminate Data

The health care community has proven that Internet data dissemination is effective in expanding the market and the demand for comparable data. HCUPnet, Emergency Department Internet Query System (EDIQS), the Maternal Child Health Internet Information Module, the Missouri Information for Community Assessment (MICA), as well as numerous vendor-developed systems have pioneered the data dissemination models of the future.

Along with effective use of the Internet, implementation of the Health Insurance Portability and Accountability Act of 1996 (DHHS 1998) is expected to transform the health care industry, and data collection models will emerge that reflect this transformation. The capacity to transmit real-time data in uniform formats will pose new challenges to data collecting and

sharing but will ultimately raise expectations by suppliers and users about the availability and value of health information. These increased expectations will drive the demand by purchasers and providers for more timely and relevant information for purchasing and quality improvement applications that will be reflected in the data models of the 2000s. This emerging data model will emphasize value-added data and will rely on collaboration and consensus to balance tensions around public reporting of comparative and standard measures of health care cost, quality, and outcomes.

Stakeholder Support

Acceptance by key stakeholders to establish and sustain the processes and relationships necessary to carry off such a complex feat is the final and most essential element for success. Partnerships and alliances that honor and preserve competitive interests while working toward the public good are crucial in making the investments necessary to address the limitations and complex issues associated with health information initiatives. In forming partnerships, the respective roles of all stakeholders concerned, including the relationship between government and the private sector, must be delineated. The issues of who pays for the infrastructure necessary to support performance measurement and how the measures are determined and defined will remain delicate and must be worked out.

GLIMPSE OF THE FUTURE: EMERGING MODELS

Models that exemplify progressive governance and ownership structures are emerging, moving the industry further along the technical and information continuum. Leading examples of these are the Utah Health Information Network (UHIN) and the California Information Exchange (CALINX). UHIN exemplifies a shared governance model and has implemented electronic data interchange among trading partners, competitors, or both (providers, payers, and physicians). CALINX was established in 1996 among California businesses, physicians, health plans, hospitals, and health care systems. Like UHIN, CALINX is putting a process in place for developing consensus standards for these basic data architectures (PBGH 2000). These organizations are charting new courses to compel "re-engineering" of local health information systems for the purposes of streamlining business and transaction costs. Although neither initiative has taken on an information-gathering function

(in fact, UHIN has steered away from resolving the legal and competitive tensions associated with data dissemination), other data dissemination initiatives can learn from them valuable lessons regarding the establishment of a consensus process in which competitors work together to achieve common gain (“co-opetition”) (UHIN 2000).

CONCLUSION

While government has a stake in health care improvement, regulatory solutions alone will not overcome the technical and political challenges. No health information initiative, present or future, will survive without a market for information. The future model must address the issues of data ownership and proprietary concerns and secure the political and financial support of the private sector. Because information—especially program- and provider-specific information—is a source of power, turf battles over the control of raw data and how it will be released can be a formidable barrier to data use (Gold, Feldman, and Heiser 1998). Separating the data suppliers from the product will thwart success.

The approaches, the players, and the tactics may differ, but there is one element common among successful models: compromise and negotiation to assure acceptance by key stakeholders in the market. As all current models have discovered, data dissemination for market decisions will continue to be a sticky issue for public and private data agencies. Agencies will continue to face the familiar paradox of data dissemination—publish relevant data or perish—and at the same time build trust with the provider community. Too far in one direction or another, the effort may be at risk of eroding political support. The ideal process or model of market-driven information, if one could exist, would be characterized by factors that balance opposing tensions related to the collection, use, and dissemination of comparative information.

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